

TECHNICAL CONSIDERATIONS FOR EMCCD AND EDRS IN COUNTRIES OUTSIDE OF SOUTH AFRICA

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Introduction

This evaluation describes key technical features of electronic Medical Certification of Cause of Death (eMCCD) systems in six countries: Australia, Namibia, Peru, Portugal, Uganda, and the United States. It catalogs how different countries approach important design decisions for eMCCD. It highlights key considerations and recommendations for the design of eMCCD in South Africa, as well as open questions that may benefit from additional research.

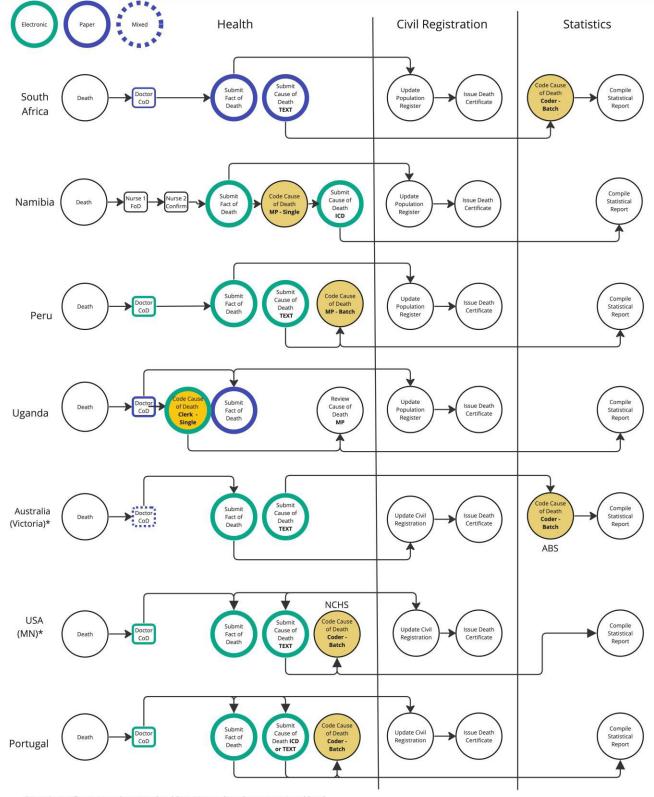
Overview of eMCCD and eDRS Systems

The workflow for death registration, cause of death (COD) certification, and production of vital statistics varies across countries. Rather than a single "best practice" design, each system has different strengths and efficiencies. In the diagrams below, the basic workflow for each country is portrayed in a flow diagram that highlights several critical events in the death registration process.¹

¹ Note the diagrams below are not full business process diagrams and do not document every step in the process; rather, they are simplified workflows to show where electronic systems are introduced and where COD coding occurs.



Death Registration and Cause of Death Flow Diagrams



*Death certificate issued at state level but COD coding done at national level



Design Consideration: Cause of Death Entry and Coding

The fundamental output from the COD certification process is ICD-coded causes of death, which can then be used for statistical reporting and for epidemiological analysis, public health research, disease surveillance and quality of care improvement. Typically, a medical practitioner (MP), either a physician, nurse, coroner, or forensic pathologist, enters data about the deceased person. As noted in the table below, this can be done either using free text to describe the COD sequence in their own words, or by choosing an ICD code directly. It can be done either on a paper form or electronically. In electronic cases, additional tools can support COD coding, such as drop-downs or coding software to suggest likely sequences. There may be validation checks to enforce certain rules, and the underlying COD may be produced in real time and displayed to the MP. To produce an ICD-coded COD, the official coding occurs in different ways across the countries surveyed, as summarized in the table below.

	Medical Practitioner Data Entry	CoD Coding Responsibility	Coding Tool	Coding Scheme	Feedback to MP	Coding Time Lag
South Africa	Paper - Text	Statistics	IRIS	ICD-10	No	Annual
Australia	Electronic/Paper - Text	·····		ICD-10	No	Monthly
Namibia	Electronic - ICD Code	MP	DORIS	ICD-10	No	None
Peru	Electronic - Text	МОН	IRIS	ICD-11	No	Annual
Portugal	Electronic - Text or ICD Code	МОН	IRIS	ICD-10	No	6 Months
Uganda	Paper - Text	Clerk (untrained)	DORIS	ICD-11	No	Weekly (Review)
United States	Electronic - Text	National Center for Health Statistics	SuperMICAR (pre 2022) MedCoder (2022- onward)	ICD-10	Yes – on occasion	~5 days to State

COD coding practices fall into three main categories based on who performs the coding. Coding by the MP who records COD, coding by administrative clerks at health facilities, or coding by a specific group of trained coders at a central ministry or directorate level.

MP Coding

In Namibia, medical practitioners code the COD directly in the eMCCD using integrated tools. Practitioners can search for ICD codes by typing in free text. MPs in Portugal can code directly using a series of ICD-10 drop-down lists, but most choose to enter free text COD.



EDRS/EMCCD EXTERNAL EVALUATION

Pro – MP Coding	Con – MP Coding
Assistance with searching and selecting correct ICD codes, with some validation	Validation rules can make it difficult/impossible to complete form when there is incomplete information
Rapid entry of data into an electronic system	Requires connectivity and hardware
No need for data capture later	Some MPs prefer to write COD on paper - limited acceptability of electronic systems
	Security concerns - password security and management of user list/credentials

Clerk Coding

In Uganda, MPs write the COD in their own words onto a paper form, which is subsequently electronically coded by a records clerk. Records clerks are not commonly trained in ICD coding, and a team of medical professionals reviews the coding weekly. This introduces the least change from the MP perspective, but significantly limits quality, completeness, and timeliness of COD coding.

Pro – Clerk Coding	Con – Clerk Coding
Little change management needed and higher acceptability of system by medical practitioners	MP handwriting and abbreviations are not easy to decipher
trained to enter COD information on paper	Clerks are not trained in coding
	No feedback on quality of CoD to MPs
	Validation rules can make it difficult/impossible to complete forms if data are missing
	Double capture of data adds workload to the system (requires MP and clerk time)
	Reduced timeliness to final coding

Central Level Coding

In South Africa, Portugal, Peru, and the United States, coding is done primarily at the national level. In South Africa, trained nosologists at Statistics South Africa (Stats SA) officially code COD from hand-written COD. In Peru, COD is coded by the Ministry of Health from free text information entered electronically by medical practitioners. In Portugal, both the ICD-10 COD and the free text COD entered by MPs are reviewed by the MOH at national level. In the U.S., official coding is done at the national level by the National Center for Health Statistics (NCHS) using ICD-10. NCHS receives information from states based on a standard U.S. death certificate form which allows for free text entry of COD.



MPs can designate an assistant to enter data on their behalf. In Uganda, coding completed by record clerks, based on COD hand-written by MPs, is reviewed at central MOH level by a group of physicians who update incorrect COD and investigate complex cases.

Pro – Central Coding	Con – Central Coding
MPs enter data either on paper or electronically in free text - higher acceptability at point of entry	Timeliness reduced by relying on smaller groups at central level
Trained nosologists do the coding and presumably higher quality coding	No feedback to inform coding at service delivery level
Ability to use additional tools to check quality of a batch of records (ANACOD, ANACONDA)	

Quality of COD Data and Coding

None of the countries surveyed reported routine use of coding quality tools such as ANACoD or ANACONDA. However, ANACONDA is used in research contexts or during specific instances where a quality review is undertaken². Australia and Portugal, for example, noted periodic reviews using ANACONDA which showed that the quality of coding was generally high. The U.S. State of Minnesota system includes a spelling check to ensure that MPs do not enter abbreviations or incorrect terms; any additional guidance on COD entry requires clicking out of the eMCCD system. Certifiers of death will occasionally get feedback from the NCHS if there are questions or concerns about the accuracy of free text information entered, but there is otherwise no mechanism for routine feedback to individual certifiers either in case of especially high- or poor-quality coding.

Key Considerations for Cause of Death Coding

- Validation rules. When using online validation rules, consider the value of having an incomplete form vs. no record at all. Strict validation rules that require all fields to be completed before submitting may result in many missing records.
- **Connectivity.** Consistent connectivity will be a limiting factor to utilize tools to assist with realtime ICD coding, such as DORIS³. However, a local version of the WHO ICD-API⁴ can be installed.
- **User preference.** Consider user behavior and willingness to adopt an "online only" approach. Ensure sufficient support for behavior change and change management if MPs prefer paperbased approaches. In some cases, designating additional users to enter data on their behalf may increase usability but introduce potential errors in translation.
- Level of COD coding. Delegating COD coding to clerks who may be comfortable with online forms but are not trained in COD coding will compromise accuracy and timeliness of data. Conducting COD coding at the central level may result in high quality coding yet may reduce timeliness of coding completion. If coding is done at central level, ensuring that MPs can enter

² <u>https://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-020-01521-0</u>

³ <u>https://icd.who.int/doris/</u>

⁴ <u>https://icd.who.int/icdapi/docs2/ICDAPI-LocalDeployment/</u>



COD using their own words is recommended to give coders the most information with which to complete coding. MPs can use data from online medical records in contexts where these exist, such as some states in the U.S., to improve accuracy of COD. Integrating COD into the electronic medical record (EMR) would provide additional efficiencies.

• **Feedback to users.** In none of the systems surveyed do those completing the COD information routinely get feedback on the quality of data they enter. Integrating a routine mechanism for feedback at the point of data entry may improve quality over time.

Design Consideration: Security

Security is a key success factor in electronic COD reporting. Due to the sensitivity of the data and the need for communication across several government ministries, systems and processes must conform to security protocols and laws implemented by each country, such as the South African Protection of Personal Information Act (POPIA) and the EU General Data Protection Regulation (GDPR). Further, all actors involved in death registration, including health, civil registration, and national statics stakeholders, need confidence in the veracity of electronic information to reduce reliance on the paper forms traditionally used to move data between ministries.

Security needs to be considered at multiple levels, including server hosting, data exchange and individual user authentication, i.e., securing who can create new records and enter COD details. In several settings, security issues presented a challenge.

Uganda reported that securing agreements for MoH to access data from the National Identification and Registration Authority delayed integration significantly. Once agreements were in place, network connectivity needed to be implemented through a Virtual Private Network portal, adding complexity to the integration.

Mistrust in the authenticity of death notifications often stemmed from weak authentication protocols. In Peru, weak password protection resulted in significant fraudulent reporting of death and contributed to mistrust in online transfer of death registration data. This hindered efforts to eliminate the requirement to submit paper MCCD forms to RENIEC to get a death certificate. However, secure user authentication protocols are well-developed and need not be a barrier if planned for during a system requirements-gathering process.

None of the countries surveyed currently require multi-factor authentication to log-into the electronic platforms. In most cases, credential issuance for authorized users is done manually. Few systems had a way to verify the certification of the user after initial credentialing was complete; Portugal's system was the only one surveyed that verified MPs against an existing registry of certified professionals at time of log-in.



	User Registry	Credential Issuance/ Management
South Africa	N/A	N/A
Australia	MOH - Jurisdictional	Credentials are managed at jurisdictional level, depending on the state. The Registry of Births, Deaths and Marriages Victoria requires medical practitioners to register with their passport or driver's license as identification, and their details are verified before they are provided with login credentials.
Namibia	DHA - stand-alone	User credentials are managed within the DHIS2 instance and are not linked to an external provider registry or medical certification board.
Peru	REINIC - stand- alone	Credentials are issued by the Civil Registration authority (RENIEC). Security of the credential management and issue is weak, leading to breaches and loss of trust in the eMCCD system.
Portugal	MOH - integrated	Access is managed through the Administração Central do Sistema de Saúde which contains certification details for health professionals. The registry of health professionals is checked each time an MP accesses the eMCCD system.
Uganda	MOH - stand-alone	User credentials are managed manually within the DHIS2 instance.
United States	Registrar - stand alone	Credentials are managed at a jurisdictional level. In Minnesota, MPs must register with the Office of Vital Records to use the 'Minnesota Registration & Certification System' by filling out the 'Medical Certifier and Designated Staff User Agreement ⁵ '

Key Considerations for Robust Security

- Invest in user verification and authentication. An up-to-date registry of validated health practitioners will ensure that only accredited MPs can log into the system. By maintaining an electronic link between the registry and the authority that issues and maintains credentials for MPs, the system can verify that users logging are accredited and active.
- **Consider Multi-factor authentication.** This adds an additional level of security by requiring user login through two different channels (e.g., password entry and one time PIN delivered to a mobile phone). This functionality is available in DHIS2 but is not commonly implemented. MFA adds additional complexity to the system yet can be worthwhile if there are high concerns of fraudulent log-in or high levels of mistrust between stakeholders.
- **Use strong encryption protocols.** Communication channels, API endpoints and websites must be encrypted, using industry standard protocols such as SSL.
- **Network Security.** Secure networks are necessary to protect data from unauthorized access by bad actors. This type of security is core to the operation of any government or private sector enterprise platform, and ministries should employ experts to ensure that their data cannot be accessed and shared. This can include the use of secure virtual private networks, and

⁵ <u>https://www.health.state.mn.us/people/vitalrecords/physician-me/docs/mcdsauagree.pdf</u>



restrictions on the use of memory sticks and other devices onto which data can be copied and removed from secure locations.

• **Develop standard operating procedures and policies** for sharing data for research purposes such as those developed by the Australian Bureau of Statistics. It is good practice to include processes for anonymization and de-identification of records, and mechanisms to relink records⁶ to demographic identity information when necessary.

Design Consideration: Incentives and Motivation to Complete MCCD

Across ministries of health, civil registration, national statistics, and among doctors themselves, there is varying use of COD data. Civil registrars are mainly responsible for death registration and the issuance of death certificates and do not typically have a need for the medically certified COD data, other than to complete certificates where it is a requirement. Statistical agencies and stakeholders within the health sector, including medical practitioners, researchers, and ministry of health officials, are better positioned to utilize COD data. However, motivation can vary given many other competing interests and demands in the health sector. Thus, completion of MCCD is often strengthened when incentivized through legal or other requirements. In South Africa, the United States, and Peru, a completed MCCD is required to get a death certificate. The necessity of moving forward with the burial process serves as incentive to ensure MCCD is completed in a timely manner after death (although quality is not necessarily assured). In the United States, each state's Jurisdictional Vital Records Offices (JVRO) is contracted by the NCHS to provide medically certified COD data and is financially incentivized to provide high-quality and timely COD data to meet the terms of the contract.

Neither Namibia nor Uganda has such incentives. In Namibia, while there is a policy requirement to complete COD within three days of death, it is not required for the issuance of a death certificate. Burial can proceed as soon as the fact of death is updated in the civil registry, following confirmation of the fact of death by two nurses. Thus, while completeness of death registration is high, completion of MCCD is estimated at only around 60%. In Uganda, death registration is not required to proceed with burial, and completeness of death registration is accordingly low.

Incentives are also important at an individual level. A common theme across all countries' implementation of eMCCD is the initial reluctance of doctors to move from paper to electronic coding. MPs are not incentivised to enter COD information where these data appear to not be used, or where MPs are not informed about the use and importance of COD information. In Uganda, doctors and nurses are incentivised with in-kind or financial remuneration to complete complex paper forms for maternal and perinatal deaths, but this does note extend to other deaths.

⁶ <u>https://ipdln.org/</u>



	MCCD is needed for Death Certificate	Death Certificate is needed for burial	Use of COD Data by Health	Use of COD Data by Statistics	Use of COD Data by Research Community	MP Incentivised?
South Africa	Yes (blind)	Yes	No	Yes	Yes (MRC)	No
Australia	Yes	Yes	Yes	Yes	Yes	No
Namibia	No	Yes	No	Yes (new)	No	No
Peru	Yes	Yes	Yes	Yes	Yes	No
Portugal	Yes	Yes	Yes	Yes	Yes	No
Uganda	No	No	No	Yes	No	Only for maternal deaths
United States	Yes	Yes	Yes	Yes	Yes	No

Key Considerations

- System level incentives. Completion of MCCD is higher when issuance of a death certificate is dependent upon certified COD, as subsequent processes such as burial, insurance claims and finalization of the estate of the deceased are important to multiple stakeholders. This introduces a significant structural incentive to complete COD information. However, the requirement may increase complexity of the death registration and can increase the time taken to register a death. Having stakeholders with an interest in the COD data involved in the system design will be important to ensure these interests are considered and built into system requirements as appropriate.
- Individual level incentives. Minimizing the burden and time requirements to complete MCCD in an online system can increase adoption, for example, by investing in an easy, intuitive user interface with minimum numbers of clicks and fields to complete. Other types of incentives to encourage timely and high-quality completion of MCCD include creating a dedicated meeting time for MPs or clerks to complete records and developing a feedback system so that those entering data get feedback on their work.

Design Consideration: Technology Specifications

In all countries, servers and databases were hosted within government data centers, commonly within the Ministry of Health or the Ministry responsible for Civil Registration. Software was most often developed and managed internally, with a few exceptions. The U.S. and Australia, which have a federated public health and civil registration system, and Portugal, which has centralized systems, employed vendors to develop their eMCCD platforms. In Portugal, these vendors were closely managed by internal ministerial software development teams which were responsible for creating large parts of the platform. In the U.S., vendor-developed systems follow general guidelines issued by NCHS, and otherwise vary in terms of software versions, types, and the level of customization completed by inhouse teams.



In Namibia and Peru, the Civil Registration Authority is responsible for the development, hosting, and maintenance of the system, while in Uganda and Portugal, the Ministry of Health is responsible. Informants were generally not privy to technical details such as server capacity, software stack or cost to maintain servers and infrastructure. However, the development and cost of the software systems were not perceived to be significant barriers. Across country systems, it was necessary to go through a formal requirements-gathering process which resulted in functional and nonfunctional requirements, and to have teams of engineers to develop and maintain the software. Several variations across system integrations, app format, and offline capability are noted below.

Integration and Interoperability. Electronic MCCD systems offer the opportunity to integrate with other existing online systems to share relevant data and reduce duplicate data entry. Countries surveyed had several different system integrations, including integration with the national ID system to exchange personal demographic information, integration with autopsy services and emergency medical services (EMS) to enable the use of autopsy and emergency services data to inform COD entry, and integration with insurance and social services to cross-reference identity details of deceased. No country's eMCCD system has integration with other health systems such as EMRs, except for Portugal. DHIS2 is a core Health Management Information System (HMIS) platform for the Ministry of Health in Namibia and Uganda. While there is potential to integrate eMCCD and eDRS data with the HMIS, the eDRS in Namibia was set up in parallel to DHIS2 in the midst of complex donor and stakeholder activities. In Uganda, the preference for paper-based entry by MPs, with subsequent online entry by a clerk, negates the efficiency of linking with the existing patient record. However, the Uganda Bureau of Statistics (UBOS) uses DHIS2 for statistical reporting and there is some integration between the DHIS2 instance used for mortality and the instance used for vital statistics. eMCCD data that has been validated and approved at central level are submitted to UBOS using an interoperability framework (zato.io).

Peru, Namibia, Uganda, and Portugal have integrated their eMCCD platforms with the civil registration system, usually the National Population Register, allowing users to pull demographic data for the decedent using a national identity number. There is no unique national identification number in Australia and the USA. In the U.S., social security numbers are used to link death records with Social Security Administration to end benefits upon death. Apart from Portugal, where SINEC interoperates with a registry of certified health professionals and the electronic autopsy and EMS platforms, no countries indicated that the eDRS or eMCCD systems incorporated other registries. Similarly, no country system except the U.S. uses data or interoperability standards to support broader data exchange across health, civil registration, and statistical agencies.

Interoperability in the Health Domain. Mature standards for health messaging are ubiquitous in the health domain, as are information exchange architectures and interoperability frameworks. One of the core emerging standards is the Health Level Seven (HL7) Fast Health Interoperability Resources (FHIR), and in the United States a FHIR Implementation Guide⁷ (IG) has been developed by the CDC and balloted for trial use for bidirectional data exchange of mortality data between JVROs and the CDC NCHS. State JVROs, including Minnesota JVRO, are beginning to move in this direction to improve

⁷ InterJurisdictional Exchange (IJE) format Mortality Data Element Mapping



data exchange, but it is still relatively nascent and requires a high level of effort to implement. The FHIR resource does not contain the name or identification of the certifying physician, coroner, or funeral director as these are not relevant for inter-jurisdictional statistical data exchange. However, registries of these actors, and other registries providing canonical lists of facilities, locations, and other codes should be used by health and civil registration systems to ensure data integrity. These registries are not commonly included in eDRS and eMCCD platforms.

App Format. While Peru and Portugal have invested in development of mobile applications, webbrowser forms were reported to be more widely used. In Peru, the mobile application pilot process has been delayed due to concerns over security, and in Portugal, the web interface is preferred over mobile given the ease of entering many discrete pieces of information, and availability of more tools, such as the integrations with the autopsy and EMS systems. The U.S. Minnesota system does not have a mobile app, as the system was developed prior to widespread mobile device use and was not designed to render appropriately on mobile devices.

Online/offline capability. Most systems surveyed offered an online only format due to requirements to connect to central servers over the internet, to retrieve and publish data to other online systems and to utilize coding assistance tools, such as an API to WHO's DORIS tool.

	Responsible Party	Developer	Hosting	Interoper- ability framework	Integrations	Software	Standards	Mobile	Offline capability
South Africa	N/A								
Australia	МОН	In-house	ABS	Unknown	Coronial System (No NPR)	State- level	No	No	No
Namibia	DHA	In-house	Ministry DC	NAM-X	NPR	Unknown	No	No	No
Peru	RENIEC	In-house	Ministry DC	No	NPR	Unknown	No	Pilot stage	No
Portugal	МОН	In-house & vendor	Ministry DC	Portugal FSC	NPR, Autopsy/ EMS	Microsoft	No	Yes	Yes
Uganda	МОН	Consultant	Ministry DC	<u>zato.io</u>	NPR, Coding in UgandaEHR	DHIS2 Tracker	JSON ⁸	No	No
United States	NCHS (CDC)	Vendor, maintained in-house	NCHS	No	Data exchange agreements w/ Social Security Administration	State- level	FHIR emerging	No	No

^e JavaScript Object Notation https://www.json.org/



Key Considerations for Technology

- Vendor/In-house software development: Both vendor and in-house software development models were employed and were successful when there was strong management from the relevant ministry. In the US, there is a small number of vendors who provide off-the-shelf platforms to states, which are often maintained by in-house IT teams.
- **Hosting:** Hosting is consistently in government data centers, which are in all cases enterpriselevel secure installations. High levels of network security and application and data redundancy are necessary.
- Interoperability and Integrations: Integration between the eMCCD/eDRS systems and the National Population Register are standard, providing the ability to look-up demographic information from the NPR, or COD data from the eMCCD system. Integrations with other registries and HIS was not common. In Portugal, where physicians could consume data from the autopsy and EMS systems, this improved the quality of the COD data. Similarly, in Australia, nosologists have access to the coronial system. Reducing duplicate data entry by leveraging canonical registries is good practice, and data exchange standards should be adopted when matured.
- Mobile Devices and Modes of Operation: Mobile applications were uncommon across countries, with only Portugal having one being used and Peru's in pilot. Development of a mobile application, if pursued, should be driven by a user-centered design approach to enhance uptake and use.

Design Consideration: Training

Training across the countries covered both COD coding practice and technology use. Content training, relevant to both paper and electronic COD entry, educated MPs on how to record COD information with the appropriate level of detail, quality, and logic. Technology training focused on the use of digital applications, including topics such as how to login and access the system, how to navigate the web application, and how to enter data. This is necessary to enable each cause to be coded according to ICD 10- or 11, and an underlying COD generated or automatically selected.

Where coding takes place at a central level, nosologists need significant training on COD coding, especially where additional sources of data besides the MCCD are used (e.g., Australia).

Countries reported several formats for training, including direct training of MPs and Training of Trainers, using both virtual and in-person delivery formats. A training-of-trainers approach involves training a group of individuals, often those who are early adopters and supporters of a new application, who will then be responsible for training others. This approach is often adopted to scale training efforts and reduce training costs. Direct training is done by a group of skilled trainers who move across locations, training end-users.





Country	Comments
Australia	Some training on coding is included as part of the medical school curriculum. Nosologists require two weeks of intensive training to enable coding for doctor certified death, and a further 6-12 months to fully develop necessary coding skills.
Namibia	Hospital administrators were trained by a small group of government staff who traveled across the country, training administrators at each hospital.
Peru	Over the course of four years, 9430 doctors were trained in entering COD information and 32 physicians or statisticians were trained in ICD COD coding. Both in-person and virtual training were utilized to support rollout. An investment of \$450,000 USD supported the roll out of eMCCD to support achievement of 86% completion over four years.
Portugal	In Portugal, a training of trainers (TOT) approach was used to reach each hospital. Training included review of common mistakes in coding, by specialty, and complemented the roll out of the system.
Uganda	Record clerks were initially trained by the developer of the DHIS2 eMCCD tracker program, and a TTOT approach was subsequently adopted. Multiple rounds of training took place, with low levels of uptake. However, a notable increase in COD data being submitted via DHIS2 occurred following the 2023 training.
United States - Minnesota	The vital records offices partner with a forensic pathologist with experience in submission of real-world COD data, who provide feedback on poorly worded COD or poor ordering of COD. Ad hoc in-person sessions were offered before Covid. No large training is offered on the web system, and online training videos are available for some states.

Key Considerations for Training

- Political will and support for eMCCD system can significantly enhance effectiveness of training (e.g., participation by key staff, senior staff).
- Training of trainers approaches, virtual and in-person training can be effective when there is sufficient buy-in.
- Consider routine trainings on both the electronic system as well as completion of COD information, in addition to training at the time of system rollout.
- Training can be an opportunity to provide feedback on common errors in entering COD information.
- Training specialist coders can be a significant investment and usually takes six to twelve months. In several countries, the central team of coders is relatively small (3-5 people); in Peru, there were significantly higher numbers of statisticians and physicians trained on COD coding.



Key Challenges and Current Landscape in South Africa

South Africa has a robust paper-based death registration system. The National Population Register is regularly updated with fact and manner of death, but COD is less reliably captured. MCCD data are not of high quality for several reasons. Insufficient training of MPs results in low-quality COD data entry, and lack of incentive to enter the data. Hand-written COD forms result in inconsistencies in data-capture and coding, and stigmatization of common diseases such as Human Immunodeficiency Virus (HIV) and Tuberculosis results in incorrect COD entry by MPs. Data for unnatural deaths are further compromised by stigma associated with suicide deaths, under-reporting of road accidents and ambiguous regulations which make many forensic pathologists reluctant to enter manner of death data. There are delays in receipt and coding of data by Stats SA, and once COD data are released by Stats SA, often after a few years, these data are anonymized and cannot be linked to medical records. While the DHA does provide fact of death data to the SA MRC for Rapid Mortality Surveillance Reports⁹, these data exclude deaths for foreign nationals, asylum seekers, unregistered immigrants and others who do not have a South African National Identification Number.

The DHA is planning to pilot electronic birth and death registration in 2023. Details of the workflow have not been shared with other stakeholders, but anecdotal reports indicate that management of Section G/Page 1 of 1, the sealed COD page of DHA-1663 has not been catered for as part of the pilot, and the process for submitting Section G to Stats SA for coding is not defined.

The NDOH has to date not been involved in the management of COD data and does not make use of COD information captured in DHA-1663 Section G, or indeed the fact of death in the NPR. There has been a large investment in the implementation of the Health Population Registration System (HPRS) over the last decade¹⁰, with over 63 million individuals registered in the system across 3150 public health facilities. Recent agreements between the NDOH and the DHA will enable HPRS to verify the identity of patients who present at the registration desks of public health facilities with a South African National Identity Number. Verification of the patient with the DHA National Population Register (NPR) will be facilitated via the Home Affairs National Identification System (HANIS) and/or the Automated Biometrics Identification System (ABIS).

The National Department of Health is planning for a National patient Shared Health Record and EMR which will be implemented across the country as part of National Health Insurance (NHI). The full rollout of the system is expected to take between 5 and 10 years.

With the implementation of NHI, there is growing interest from NDOH in data sharing with the DHA and the National Population Register, and the implementation of electronic birth and death registration provides an opportunity to implement eMCCD and strengthen links between NDOH and DHA. Complementary investments in the digital health ecosystem are necessary to make this work, including integration of the existing NDOH facility registry which covers all private and public sector health facilities, the Human Resources for Health (HRH) registry (also known as the Provider Registry), and interoperability mechanisms.

⁹ https://www.samrc.ac.za/research-reports/rapid-mortality-surveillance-reports

¹⁰ https://pmg.org.za/committee-question/19974/



Home affairs has implemented a citizen eServices portal which is used for appointment bookings, applications for identity documents and passports, and payments. The platform uses secure multi-factor authenticated logins for citizens, requiring one-time-pin verification via mobile phone.

Relevant Findings for the South African Context

As South Africa considers introducing an eMCCD/eDRS system, learnings from other countries indicate several possible improvements can be made to the existing process:

- Digitization of the entry of COD has the potential to improve quality; MPs generally prefer to enter COD in free text, rather than use structured coding tools. Checks for spelling errors reduces the use of abbreviations and other errors, and real time feedback on validity of the underlying COD is useful.
- A hybrid model can work, with some deaths being registered and medically certified electronically, and the remainder through paper forms.
- When COD data are submitted for coding electronically, where auto-coding tools such as IRIS are used, and the coders are well trained, it is possible to complete coding within 1 to 6 weeks, as is the case in Portugal, Australia, and the U.S.
- If MPs enter data electronically, a robust method to manage credentials and access must be implemented, integrating with the health professional certification authority. In Portugal, each time a user accesses the system, they are validated against the registry of health professionals managed by the Administração Central do Sistema de Saúde, similar to Health Professionals Council of South Africa (HPCSA).
- Maintaining the current DHA eservices portal use of MFA is good practice.
- It is possible to integrate the eMCCD system with other data sources, such as autopsy and EMS systems, and this improves the quality of COD data. Integrations should be planned before the eMCCD system is implemented.
- Emerging international standards for mortality data should be implemented to align with international best practice promoted by the CDC and WHO.
- A mechanism to provide NDOH and medical research institutes access to aggregate and individualised COD data will increase data use and increase motivation for completion of MCCD data.
- Best practice for eMCCD is to have the eMCCD system separate from the civil registration system, and to implement interoperability between them to allow verification of identity and retrieval of demographic and COD data.



Areas for Further Research

This survey of external countries points to additional areas of research that may inform the design of an eMCCD system for South Africa.

1) Feedback as a motivation for higher quality data: To what extent does giving feedback to MPs on COD coding improve coding?

In Portugal and Australia, there are mechanisms in place to follow-up on incorrect coding, although these are not routine. Feedback to the MP and health system units on quality of COD data entered by the MP is not common but has the potential to improve quality with a feedback cycle, showing MPs that the data they enter is being used, and giving assistance and training on coding. An initial step could be the analysis of a tranche of 1663 forms from DHA or Stats SA to identify characteristics of COD data entered by doctors, and analysis of COD statistics per doctor.

2) Time savings, quality improvement and acceptability of digitized COD data entry: How much time could be saved and what level of quality improvement could be gained by implementing electronic data entry, and how acceptable will MPs find electronic entry, either in free text or using ICD coding tools?

Implementation of eMCCD in other countries has improved the timeliness and quality of COD data.¹¹ There may be an opportunity to measure improvements through a small pilot in South Africa. A threearm trial could measure differences in quality and timeliness between paper-only COD data entry, paper and free text electronic COD data entry, and paper and electronic ICD-coded COD data entry. The feasibility of duplicate data capture in this pilot scenario will need to be assessed. Bias introduced by the selection of MPs who are willing to enroll in the trial, and by the duplicate entry of data must be controlled for.

3) Interoperability with other systems: To what extent can an eMCCD system exchange data with other registries in South Africa? What is the maturity and accessibility of these registries?

Further research is needed to understand the maturity, accessibility, and interoperability of existing NDOH registries, including the facility and Provider/HRH registries. Similar research is needed to understand the technical process of exchanging data with Stats SA, and interoperating with various DHA platforms, primarily the NPR, and potentially others such as the Border Management Authority system. The existence of, or potential to create, registries for traditional leaders and undertakers should be investigated.

¹¹ https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-018-6264-1